

Spark

april/may 1998

The newsletter of Hackney Council for Voluntary Service

Disability - Special Edition

To be Disabled or not to be Disabled?

Well, it can depend on the following;

How many steps to climb up or down!

How many social events to miss!

How many wrong care assessments!

How many ideas and dreams not to share!

How many unnecessary pills to swallow!

How many independent advocates there are!

How many times you have to define sickle cell!

How many words to read and on who's lips!

How many times you are stared at, or spoken about, as if you're not there!

How many holes in the road and curbs to manoeuvre over in the street!

How many explanations to give that "yes I have disabilities, but I am a mother and have a right to school events"!

How many times you can tell your employer the school bus did not pick up your child with a disability!

How many times a day you carry your loved one up and down the stairs before you fall!



"You won't believe this.....the accessible bus comes tomorrow"

by Leyla Laksari

Contents

Introduction	3
Interview	4
• Caroline Nelson	
Local Disability Initiatives	5
Arts & Disability and Poems	7
Refugees & Disability and Benefits	8
Policy and Transport	9
Profile	10
• Joint Planning Unit	
• TLC	
Hackney CVS News	11
• Voluntary Sector Review	
Community Care	12
Volunteering & Disability	14
Funding News	16
Community News	18
Events and Recruitment	20

Hackney CVS STAFF

Adiaha Antigha
Director
Suzanne Adofo
Administrator & Finance Worker
Rimple Poonia
Community Care Development Worker
Leyla Laksari
User Participation Worker
Kristine Wellington
Funding Development Worker

Elizabeth Bayliss & Marika Mason
Consultant Fundraisers

HCVS receives financial assistance from: Joint Finance, The Bridge House Estates Trust Fund, Heart of Hackney and the
London Borough of
Hackney

This issue of SPARK was co-ordinated and edited by: **Leyla Laksari**. Design & production by: **Rimple Poonia**

Views expressed in this publication are not necessarily those of HCVS.

The disability movement in Hackney as well as globally, is strongly challenging the medical models of disability, campaigning for civil rights and equal access to services which the rest of the public take for granted. This issue of Spark highlights some of these efforts and hope to add to the debate on;

- the values, principles and practical means we need to develop to address discrimination and social inclusion
- how to create greater access to information, knowledge and skills
- sharing power so that all the struggles for positive and inclusive societies have a chance.

There are currently a **wide range of programmes and initiatives** aiming to improve life for Hackney's residents including: major regeneration programmes for Heart of Hackney, Haggerston, Hackney Wick and Stoke Newington; European funding programmes such as Objective 2 and the URBAN initiative; the new Health Action Zone for East London; the Council's Community Care Plan and the Voluntary Sector Review.

Up until now people with disabilities have at best only marginally been involved in shaping these programmes and plans, and at worst, have been completely excluded. As a priority Hackney CVS will try to support all groups and individuals working to achieve this.

None of the staff team who produced this issue are people with a disability, but most of the material included has involved significant contributions from people with disabilities (locally and nationally) and we thank them for their contribution.

Contact HCVS for large print copies of the articles in this newsletter or for tape versions of the main articles.

We All Suffer From "UN-LEARNING DIFFICULTIES"

Poverty and lack of access is a huge issue in Hackney. Working with users, carers and many practitioners in Hackney I have hardly met anyone who has given up; we have only one option and that is creating real partnerships. One thing's for sure, none of us can say that we can live our lives without thinking about disability. We need to take on the challenge of learning a new culture that thinks "access first" and remove our UN-LEARNING DIFFICULTIES.

In this day and age it is possible to make things accessible with signs and symbols to buildings and transport, yet despite some good efforts and even though much has shifted culturally around integration and inclusion, many measurements for access are still incorrect.

Access is not just about physical disabilities so that our children can attend local integrated schools, or combating the loneliness and isolation of the elderly, but also about changes in mental health laws and regulations that prevent people having access to jobs, mortgages and insurance, or in the case of people with learning difficulties giving witness testimonies. **Access is about civil rights and equality.**

Statistics.....

Estimates suggest that there are about **20,000 people with disabilities living in Hackney**, including just over 8,400 between the ages of 16 and 64. Older people age 65 and over make up 11% of Hackney population and nearly 10,000 households in Hackney have at least one member with a disability or long term illness. This data can be broken down further to show estimated numbers of people with learning difficulties, mental health, HIV and AIDS. Yet, despite these massive demand, **only 2% of Hackney public buildings are accessible, only 30% of highways have good quality dropped curbs and just 6% of housing stock is adapted.**

Access must be a priority

At HCVS we recognise that there is a great need to co-ordinate work on access to service and have set up an **Access Group** which brings together user led disability and advocacy organisations and individuals. The group aims to have a strategy which:

- has a clear vision based on community empowerment
- has objectives that build on achievements rather competition
- has resources so it is not set up to fail
- is independent and user led and negotiates rather than colludes
- is inclusive and holistic so it does not discriminate
- is accountable and thinks of solutions so it can have sustainable future

This initiative is based on the work of user and carer involvement in health and social care and work with the Disability Users Forum who have campaigned vigorously to keep the agenda on access alive. The group has submitted a bid to the European URBAN Initiative to fund a development post.

If you would like to be involved with the Disability User Forum, the Access group or more information contact: **Leyla Laksari at Hackney CVS Tel: 0171 923 1962**

In Hackney we have diverse and versatile communities with a wealth of knowledge and abilities. There is a lot to share and build onto the struggles and actions of people with disabilities and although we don't have enough space to do justice to all of these, some are reflected in this issue of Spark; it is a first attempt and hopefully there will be more !

(Sources of data are from the C&H Community Care Plan, Poverty Profile in Hackney, Hackney Transport Policies and Programmes - available from the Council and HCVS)

HOME SWEET HOME?

The **Estate Regeneration Strategies (ESR)** and **Comprehensive Estate Initiative (CEI)** are not just meaningless initials, they are about future homes for many Hackney residents.

Some are for families with a member with disabilities, some of whom have been waiting for rehousing for a long time whilst their quality of life and well-being are reduced daily. Although some very important housing policy and strategies in Hackney have been developed to respect these unmet needs we have **testimonies from residents and families who are raising issues about how these policies are being put into practice.** They highlight an urgent need to look at implementation stages of the ERS and CEI and to assess how:

- good practice on access is being achieved and monitored
- planning permissions and local negotiations with housing associations are promoting the short term and long term needs of people with disabilities in Hackney.

The Disability User Forum will continue to **encourage regeneration managers to ensure the need for accessible homes is met** so as not to further the social exclusion of Hackney people with disabilities and their families. If you are interested in getting involved in promoting good practice in this area of work contact:

Leyla Laksari at HCVS Tel: 0171 923 1962

Interview with Caroline Nelson - Co-ordinator of CHOICE in Hackney
"working for equality and integration"

Caroline Nelson is a founder member of Hackney African Caribbean Disability Association. She also teaches Braille, is a member of the management committee of a number of organisations including HCVS, and a Voluntary Sector representative on the Disability Joint Executive Team.

I started the interview with Caroline by asking her which issues she is concerned with and what good practice she can recommend, including positive action for promoting equality. **However the focus of the interviewed changed to something close to her heart and valuable to all of us - how she became a Black feminist advocate for people with disabilities !** In her words the story goes as follows.....

"I started from scratch. I was very isolated as a mother and a disabled person. It must have been some 14 years ago when I was approached as a blind person to attend all these high powered meetings to represent people with disabilities. The person who introduced me to it said she would be there to support me so we went along to the first meeting. I remember so much paper was being shuffled around and they all seemed to know a lot. They were talking about a decision they made or things to do next but **I had no way of knowing how I could contribute; I was silent.** The next time there were so many other new things being discussed - so I was quiet and I was still thinking how could I represent people with disabilities? I had no group to go to for support and feedback. Well, the third time I knew what to do - **I resigned!**"

"I had my baby and I was then teaching a few hours of Braille. I was meeting more people like myself: Jewish, Asian and African Caribbean who were talking about other issues too, as well as wanting to learn Braille. For transport I was using Dial-a-Ride, and meeting other people with disabilities and older people; there was always some sort of heated discussion going on about access and social attitudes and the difficulties different people were facing and our ideas for change".

"Closer to home, I was a mother taking my child to nursery and continuously being approached about how I manage to be a blind mother. People asked me questions, checking me and asking me to perform and show how I cooked and did other things. I

used to stay back to explain to all these different parents and enlighten them on disability issues after others had gone home to finish their washing and cleaning. I was always late home until I realised I had the right to say no. I began to say 'if you are interested, do it some other way, educate yourself, go and read about it, I don't have to be your easy option all the time'."



"**Being a black woman, with a disability you get discriminated against, overlooked and tokenised three fold.** It was lovely to meet other Black people with a disability - we connected well and understood our isolation and wanted to do something about it. We had a problem and we had to find solutions.

We formed the **African Caribbean Disability Group** as a self help group with nothing. I got £20 for a training session, which went a long way in buying stamps and paper. Then we got help to put in a small grant application for £500 and now we meet regularly and sometimes have outings with our families to fight isolation.

Some of us have other disabilities or have had a stroke, so when we are asked to be representative it's not easy at the best of times. Some of us are not assertive enough to resign when we should, so we stay silent rather than look stupid, hoping we can contribute better next time.

We need Chairs of meetings to respect the needs and understand the dynamic of the meeting so that it does not become oppressive. When we are asked to go to meetings we now can ask 'do-gooders' what support they are going to provide. We certainly need minutes of meetings well in advance so that we can prepare our contributions".

I asked Carolyn whether she voted in the last election? "I did, the venue was reasonably accessible to me so I went along; they told me that someone would come and read out the options for me. I then had to tell her who I wanted to select, and she marked it and put the voting slip in the box. I felt really silly and it certainly was not confidential; I felt I was being led". See page 19 'Access to Democracy'. Interview by Leyla Laksari

"Hackney Road, take me home to the place....."

Linda is an active member of the Disability Users Forum, which is campaigning on accessible and accountable transport, buildings, health and social care services.

"I live near Homerton Grove Fire Station where **the curb is 4 to 5 inches high.** I have to travel in the road or go back cross the park to get home. Well, at night time it's a joke. Near the Scrap Project the curb is more than 6 inches and **going to the chemist is hell** - I have to cross to the other side, go past Hackney Hospital and then cross the main road, it takes me a long time.

The worst experience is at the top of Morning Lane where there is an island to cross to get to Mare St. It is very badly planned. I can only get through it sideways. I also block other people creating danger for children or parents with pushchairs. So I have to go around the ramp against the traffic and then cross to the other side just to find a very sharp curb. It's horrible and a nightmare even if some one is pushing you.

A year ago I volunteered to the Council to be involved in measuring access to roads but I have heard nothing since! If I can't get out of my house I can't participate. That is where integration starts or stops!"

by Leyla Laksari



Hackney Sparrows

Hackney's Sparrow can sing and fly but also score.

"It seemed like a few days ago when I was introduced to wheelchair basket ball" says Amir Laksari, the secretary and a player with Hackney Sparrows Wheelchair basketball.

The Club was founded in 1987. In a 10 year period the Sparrows have managed to train more than 100 people with disabilities from Hackney and East London, enter several teams in British National Leagues, win several National and International tournaments and have become established as one of the best teams in the UK.

Wheelchair Basketball is the most popular Disability sport world-wide. There are more than 100 teams in the UK. Hackney Sparrows are the only team in central London, but have lost many of their players due to lack of funding. Hackney Sparrows have been supported by **Heart of Hackney and Regeneration And Partnerships (LBH)** to attend the European Championship in Cyprus in May 1998.

"Alad Sanusi from Haggerston Leisure Centre has donated 6 practice basketballs. **We need all the support we can get in order to survive and continue with our success**" says Amir. The Sparrows hold training sessions every Wednesday and Friday from 6 - 8 pm at Haggerston School, Dunloe St, E8. If you would like to participate in the team's activities or offer financial support please contact Amir on: 0181 - 889 7722.

Hackney Sickle Cell Support Group

Its members are working and campaigning to raise more awareness and involvement within all the communities and services in Hackney. They specifically want to highlight the need for donors from members of Black African and African Caribbean communities for blood transfusions and bone marrow transplants.

"It really makes a difference of life or death for our children" says Louisa Roberts member of the support group and the Disability Users Forum. We are also having a fun day at Victoria Park on 16th August, open to everyone. We need all the help we can get to promote our children's needs so that they are not discriminated against. For more information contact Sickle Cell and Thalassaemia Centre at Homerton Hospital Tel: 0181 510 7412

Hackney Sickle Link (HSL)

HSL is a shared care service and support network for children & their families living with a sickle cell disorder. It is recruiting people living in the local communities to care for children over a period of up to 36 days a year. For more information call: 0171 241 4022

CHOICE in Hackney

Is a voluntary sector organisation providing advocacy to disabled people. It is run by and for people with disabilities to support them to live independently and make choices about their own lives.

Tel: 0171 613 3206

Minicom: 0171 613 3208

Hackney Disability Consortium

This consortium is based at the Alfred Heath Centre to support the development and co-ordination of:

- Hackney Sickle Cell Group
- Hackney Disability Alliance
- Hackney African Caribbean Group for People with Disabilities

For more information contact Claudette or George: Tel 0181 525 1195

HAMPH

HampH is a Hackney Association for People with Learning Difficulties - a forum to discuss and have open debates about the quality of services in Hackney for people with learning difficulties.

Its members were involved in starting Lauriston Road: Britain's first community home for people with all degrees of disability and they also campaign for user and carer involvement in planning and monitoring services, such as the Council's 5 Year Plan for Day Services. HAMPH have raised concerns about the Plan with Nette Carder (Director of Adult Community Services - LBH) including issues around;

- personal care
- facilities
- transport
- communication and
- users being shuffled around different centres.

For more information call Andrew Roberts Tel: 0181 986 5251

Disabled Kurdish and Turkish Refugees Project

The Disabled Kurdish and Turkish Refugees Project came to an end after holding an open day at the Alfred Heath Centre on 17th March 1998. Some of the disabled refugees who participated in the research turned up and made their final comments. The project was funded by the Lottery Charity Board and the open day sponsored by HCVS. The project's report will be published shortly and be available from Halkevi Cultural Centre Tel: 0171 249 6980

Plain facts

Plain Facts is a magazine about research for people with learning difficulties and their support. Each issue of Plain Facts covers the findings of a different research project. Plain facts uses pictures and a clear language to make information about research easier to understand. It is on tape, is produced 6 times a year and is never more than 650 words. It is free to self help and advocacy groups and to date it has covered lots of different things including:

- housing and support
- living with another family
- making complaints
- supported employment
- college and adult education
- Direct payments
- having a say about your housing

We thank the Norah Fry Research Centre in Bristol who kindly sent us copies of Plain Facts. For more information contact Leyla at HCVS or Jane or Ruth at Plain Facts Tel: 0117 923 8137

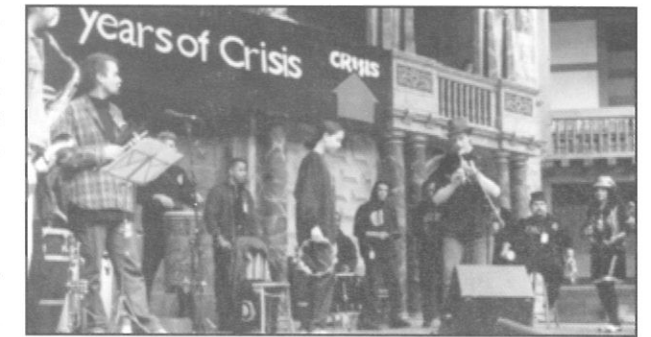
Core Arts & Core Sound

Core arts is an expanding and multi-talented ensemble of artists and musicians based in Homerton, who all have one thing in common - an alternative approach to life, art and mental health. Over the past five years Core has established an excellent reputation amongst health professionals for working effectively with people with severe and enduring mental health problems.

This success has persuaded Professor Anthony Clare, presenter of 'In the Psychiatrist's Chair', to become Core's first patron and prompted an invitation from the homeless charity Crisis to perform at a recent gig to celebrate their 30th anniversary. The event at Shakespeare's Globe also starred Paul Weller, Beth Orton, Rory Bremner and The Medieval Babes.

Increasing referrals from GPs, Psychiatrists and Social Services Departments is proof that concentrating on an artistic agenda, unclouded by therapeutic concerns, enables some of the most vulnerable and deprived people in the community to tap into their creative energy and produce results which not only give pleasure and inspiration to many others but also contribute to the regeneration of the area.

However this increase in demand for the services finds our studios in Homerton busting at the seams on most days which means that we'll probably be looking for a bigger home in the near future. So if you have a spare building or would like more information on Core Arts contact: 0181 533 3500



poems

GO ON!!!!!!

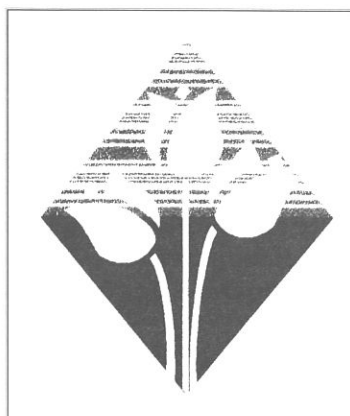
Wake up my feet
another few miles
to go
Wake up my feet
another place
to be
Wake up my feet
for the chariot
you will be
in the days of hopelessness
in the days of plenty
in the land of honey
there my feet we
will be
Wake up my feet
for the music is booming
the sunshine is streaming
and love we will find
in the harvest of the
hearts
Wake up my feet
for the body is one
Wake up my feet
Wake up my feet.....

by Keya

My friend
See how I fly so fondly
All can hear the song of my fame
Though in all places I reach out and
integrate
Yet... yet in the heart of my soul I
drown in a hundred wishes of being.

A Farsi poem by a disabled refugee.

ای دوست بین چه مست در پروازم
بشیرده نشود در هم جا سازم
هر چند هم جا با همگان هم سازم
در دل به خدای عرق صدها رازم



A haiku

Disabilities
Both hidden and visible
Are not handicaps

by Christina Domingo

When things go wrong as they sometimes do,
Remember it's not always up to you.
God is our source, that much is true. So just
remember He loves you
His son, Jesus Christ died on the cross to save
me and you
What a wonderful thing his love is so true.
Remember one thing when you are feeling
down and blue;
He is always right there walking with you
Just keep on praying; though sometimes it
may seem hard to do.
Put your trust in him and he will always see
you through.
Oh what a beautiful thing that his love is so
true.

True, true, his love is so true.....

by Brenda Nelson of the African & African
Caribbean Mental Health Users Group

Refugees and disability

We have contacted the British Refugee Council regarding the different policies and strategies to assist refugees with disabilities. They have sent us 35 pages of extracts from a **United Nation** document informing public policy makers how to incorporate and integrate the needs of disabled refugees.

The pages describe different stages and **steps for prevention and intervention, examples of good practice around prevention, identification and assessment and check lists** so that the injuries and harm suffered by refugees, physical or emotional do not become impairments, disabilities or handicap.

Policy-making and planning for disabled refugees should involve not only decision-makers, but also members of organisations working with the disabled. It highlights the people of both the host and refugee community and says **the success of community based programmes of prevention and rehabilitation for disabled refugees will depend on the understanding and participation of the whole community**, not just those immediately affected. Disabled refugees and their families should not be forgotten and their potential contributions should not be underestimated. "A community's attitudes to the disabled is representative of its attitude to life".

In partnership with the **Refugee Womens Association** we are developing work with new arrival refugee women to access services and skills and opportunities, especially those who suffer from mental health. In partnership with the African & African Caribbean Users and Survival we are looking at opportunities of linking Black community projects with mental health provision.

Also many members of refugee communities who live and work in Hackney are **raising consciousness and struggling to bring an end to the arms trade**. Countries and communities are maimed and devastated through arm deals and no resources left for the surveyors to rebuild their community. Many of us believe the money spent on defence could very well be used here to support people with disabilities and building inclusive societies.

For more information please contact Leyla at HCVS or Refugee Council on: 0171- 582 69 22

Benefits

Harriet Harman, the Secretary of State for Social Security, met with users on Friday 20th March 1998, first day of Spring. This much awaited meeting was originally scheduled to take place on 20th February.

People with disabilities and representative of disability organisation arrived prepared and had faxed questions to Harriet Harman in advance and looking forward to the two hour meeting. Unfortunately the Minister arrived an hour late and left early looking rushed and unhappy, having not covered even half of the questions. Asking some of the participants after the meeting what they thought about it - **"I don't think she expected people with disabilities to come prepared, so was thrown with the challenging questions"** and **"I think it's an insult to disabled people... after all the time and preparation that has gone into organising this meeting, she couldn't even bother to answer the questions."**

Questions were asked about the Benefits Integrity Project (BIP) with many participants calling for the abolition of the controversial project. **Whilst acknowledging that there had been fundamental difficulties with the BIP, the Minister made it clear that there was no question of its abolition.**

The Government's plans include the possibility of taxation, cuts and means testing of disability benefits although often they are not extra earnings but simply an attempt to cover the extra costs that people with disabilities have to ensure that they can get around and have minimal care. There are rumours that **Local Authorities may have to administer DLA**. It is hard to believe that they can take on all the new assessments when they already have long waiting lists for assessing needs.

A recent report from the Government's expert advisor's quoted in the Guardian newspaper on 13th March, stated that 70% of people entitled to DLA are not claiming it. Ministers are alarmed by the growth of the bill for sickness and disability benefits which now stands at £24 billion (£4.4 billion for the cost of DLA alone). The advisors are calling for root and branch reform and say benefits should be restricted to "the most severely disabled" and that "they are aware that the public purse is unable to satisfy all mobility and care needs of all people with disabilities and that the government is faced with a major challenge in determining priorities and in making difficult choices".

Members of the **Disability Users Forum** were asked what they thought of the Government's possible benefit cuts. Bernard Saltmarsh said "It's like juggling balls and being bad at it. The Minister's throwing them all in the air to see which one will land. The reality is that many elderly people and people with disabilities just don't claim." Another user said, **"the Government's attitude is not about empowering independent advice agencies, but making the forms even more complicated, so people find it impossible to deal with or go to your GP, even if you have one!"**.

Who is 'Disabled' under the Disability Discrimination Act?

Legal definition: In law, a person is disabled if he or she has a physical disability (including sensory impairments such as sight or hearing or mental impairment, learning disability or clinically well recognised mental illness) which has substantial and long term adverse effect on his or her ability to carry out so called 'normal day to day tasks'.

"Substantial" is a matter left for judicial interpretation. Long term will mean 12 months but the act does not include people with HIV but with no symptoms of AIDS; mild forms of impairment such as cerebral palsy, people who others perceive to have a disability. The Act concentrates on what people cannot do and on discrimination and how to deal with it. The new government

manifesto promises to "Support comprehensive civil rights for disabled people against discrimination in society or at work, developed in partnership with all interested parties". This will indeed have a far reaching implication.

City & Hackney's Community Care Plan states "Actions to meet the requirements of the DDA will take place over the next two years. The Act makes demands on employers to ensure that the recruitment and employment rights of people with disabilities are enhanced, as well as developing educational provision and access to other services".

(source: Extracts: Update from Scope Campaign Dep. Tel: 0171 636 5020 and C&H Community Care Plan).

Transport

According to the 1991 census over 62% of households don't have access to a car (80% in some wards). Bus services are the most important motorised means of travel. 45% of all journeys in the borough and 70% shopping trip are on foot or by cycle.

More than 14% of people in Hackney are affected by physical disabilities and 3 out of every 10 traffic casualties are pedestrians. Every year each local authority have to produce their local **Transport Policies and Programme (TPP)** and put it out for local consultation in order to receive a grant from central government. The Council states it's intention is that all transport plans in the borough should in future be reviewed in terms of the improvements they offer to local users in the following order;

- Children, elderly people and people with disabilities
- other pedestrians
- cyclists
- public transport vehicles, emergency vehicles
- public services
- local authority business collections and deliveries
- resident's cars
- non-local motor traffic

The TPP has a section on accessibility and security highlighting, information and issues about people with disabilities, the elderly, women and black and ethnic minority communities.

There are 2000 people in Hackney who have physical disabilities which require them to use wheelchairs. Further groups of people, particularly the elderly (one in six Hackney residents are over retired age) and infirm, have restricted mobility, people with sight and hearing impairments.

Existing Facilities

The main services that are provided for those with disabilities are :-

- Dial -a -Ride Services (a door to door, wheelchair adapted minibus that can be booked in advance).
- Taxi card Scheme (usage of ordinary black cab at a reduced rate)
- Permits for people with Disabilities (free travel after 9 am on London Transport and British Rail)
- New "Plus Bus" Service a 2 year pilot scheme of a fully accessible low floor bus for fixed routes
- Co-ordination Centre for Accessible Transport a "one stop shop" for information on accessible transport and co-ordination centre run by Hackney Community Transport.
- Wheelchair accessible buses
- Five mobility bus routes (usually operating on one day a week)
- Orange badge Scheme (500 disabled parking bays)

Hackney communities, users and carers have been campaigning for accessible and accountable public transport, and have contributed to the development and good practice of the above mentioned services and towards keeping the debate alive and promoting a holistic approach to transport policy co-ordination, uses of minicab firms training of transport workers in disability awareness. There is also a strong move towards building an independent user movement that is able to promote its own agenda of accessibility, have access to policy making, contracting and play a role in monitoring and evaluating services.

Lorraine Langham, Executive Director (LBH) is responsible for transport and is responsible for overseeing yet another study on transport in Hackney, due to be commissioned shortly. For more information and sharing ideas contact: **Leyla Laksari at HCVS Tel: 0171 923 1962** (extracts from Hackney Transport Policies and Programme 1998/99.) For a copy of the report contact Directorate of Environmental Services, LBH, Traffic & Transport Group, 161 City Road, London EC1V 1NR.

City & Hackney Joint Planning Unit

Au Revoir and good luck to Jane Tilston

who is leaving City & Hackney Joint Planning Unit after five years and moving to the Community Relations & Health Promotion Directorate of East London & City Health Authority to work on health promotion in the areas of mental health, older people's and women's health.

Some of the highlights Jane will remember include working with ;

- a group of **carers of older people concerned with improving respite care**. One achievement was the provision of new facilities dedicated to respite, recognising carers' views that respite is a 'specialist' service
- parents of children with disabilities who were raising issues about support for parents from the time when their child was first diagnosed. A 'supporting parents' day was organised jointly and helped increase awareness about parents' self defined needs within joint work.
- **older people around accident prevention work** - geared to the prevention of falls in older people - has led to this good practice being shared with other boroughs and to the development of interactive theatre with older people, involving them in defining what is effective.

Jane will miss the many people she has met in the course of her work, what she has learned from the experiences of services users and carers, and from the skills and commitment of the many workers with whom she has been involved in joint work. *City & Hackney has a vibrant joint working community and long may it continue and prosper!*

....and Welcome to Rachel Salmon

who has recently started working in Hackney as a Joint Planning Officer. **Rachel writes....** I am a disabled person and have had experience as a service user, so I know how frustrating and insulting it can be, when you are not getting the kind of help you need to be able to get on with your life.



It is my job to ensure that the Health Service and the Local Authority, particularly Social Services and the Housing Service, work together in planning and delivering **Community Care Services in Hackney**. I'm responsible for **organising the Joint Executive Teams for Mental Health, Physical Disabilities, Learning Difficulties, Housing and Transport Services and the Joint Finance Programme**. A review of Joint Planning is currently underway and we would be very pleased to hear any views, ideas and suggestions as to how we can improve Joint Planning, to make it more relevant to the needs of those who use the services. Please contact me at The Joint Planning Unit
Tel: 0171 301 3162

TLC Care Attendant Service

TLC (Triangle, Lockwood and Crossroads) provides four services. We are perhaps best known for the **direct support we give to people with disabilities**.



Mary Julian

This includes personal and domestic support for the person with the disability and respite breaks for their family carers both during the day and at night. **Our service users include people with learning difficulties, physical disabilities, AIDS, dementia and increasingly with functional mental health problems.**

The introduction of Community Care in 1993, while ensuring a much broader and more systematic assessment of Hackney people, radically changed the way we work. Recent changes from block contracts with Social Services to total **spot purchasing** has added to the complexity of managing a viable business. **Hard pressed Social Services budgets** have reduced the scope for flexible care packages. TLC is able to provide some extra support to enhance the quality of life for some of our service users. This may include social outings or visits to friends. Recently we used this fund to help an elderly person to make the transition from her flat, where she had lived for 35 years, to a supported home.

Another service TLC provides is for partners and family **carers** and includes support and advice both to groups and individuals. Statutory funding for this project ceased last year and we are actively fundraising to maintain this valued service. In 1997 we launched the **Stroke Project** which meets at the Sharp End on Mondays. TLC is proud of its ability to recognise a gap in services and will try to find a way to fill it. One of our specialist area of work is with **people with Dementia**. We recognise that this sometimes challenging work is poorly understood and to address this, a training unit, initially funded by a Mental Illness Specific Grant, was established in 1991.

TLC staff also represent the voluntary sector in Joint Planning. Christine Kaltoft (Director) is a representative on the Older People Joint Executive Team (JET) and Mary Julian is on the Disability JET. If you would like to know more about TLC or have issues you would like us to take forward into joint planning please contact: **Mary Julian or Christine Kaltoft Tel: 0171 729 6335.**

Voluntary Sector Review

HCVS 's first Voluntary Sector Forum was on March 17th at Sutton House and 30 people attended. We looked at: LBH's Review of all funded voluntary and community organisations, Regeneration and the New Deal

The main discussions focused on the forthcoming review process and how it will impact on the sector and on individual groups. The main concerns were:

- the hectic pace of the review process and its timetable (April - June for the first phase of visits) seems rushed and possibly unrealistic
- the appeals process, it was agreed that the voluntary sector should be represented as observers who are able to comment on the process and its fairness or otherwise
- there was discussion on the role or involvement of council members in the appeals process. Agreed that members are the ultimate point of appeal
- the councils strategic objectives and priorities - important that groups are clear what these priorities are, agreed to ask for a summary of these priorities
- there was also concern that officers carrying out the review be properly briefed and trained particularly in issues affecting the vol/community sector
- the resources, support and training available to groups to enable them to meet the criteria particularly in terms of time to get all of the requirements in place when so little support has been made available in the past (the councils own quality standard training was cited as an example that should be promoted)
- premises issues were also flagged as a major concern - the shortage of physical space, the serious limitations around access and the problems re the availability/cost of premises locally. Also some groups are now being asked to pay market rents after having had special arrangements often for many years, there was concern over how this will be resourced

HCVS was asked to raise the above issues and concerns of the forum with review officers, to monitor the review and to feed back to the forum which will meet again in June by when it will be in progress and there will be real examples of how it is working. Watch this space! Adiaha (Director of HCVS) also reported that she had been asked to be involved in running a training session for officers conducting/participating in the review.

Subsequently the training session was held on Tuesday March 31st at the town hall, was well attended and led by Lisa Christensen Executive Officer.

Key points were:

the review is a corporate exercise and wherever possible it would be standardised across all service areas. The review takes place in the context of the council's core values and priorities which need to be made explicit, summarised, published (both at service and corporate level) and made available to all groups

- the review is about the monitoring/assessment of performance, potential for development and accountability and it is being conducted in the context and spirit of the added value of and developing partnership with the voluntary/community sector
- the review is about supporting and developing rather than policing groups and is an opportunity for stock-taking, the collection of baseline data on the sector including identifying gaps and duplication, as well as an opportunity to build capacity
- information from the review will help the borough to assess best value and to commission services from the voluntary/community sector as of April 1999
- the review will enable the new strategy and commissioning teams to respond positively to new groups and innovative work in the sector
- the review will be the basis for strategic development of the sector and long term alternative funding strategies will be looked at with the support of the LBH
- the appeals process should include independent voluntary sector observers (LVSC are to be approached.) Also that appeals will take place during the process as well as at the end. Information on the appeals process will be made available to all groups
- premises issues are an important aspect of the review process and understanding/ flexibility are needed around the limitations/difficulties faced by groups in Hackney are important. Also that information from the review about premises issues should inform a strategy for addressing the needs of the sector with regard to premises.

Review Timetable:

- March 1998** funded groups to receive a letter alerting them to the review and the criteria for assessment.
- April- June** Review meetings and initial contacts with reviewing officers established.
- July - September** meetings held to discuss contracts 1999, 2000 and 2001
- October** Recommendations to members re: which groups are to receive funding and which not.

Contact **Adiaha** at HCVS for more information.

Interview with Dr Gaby Tobias, Co-Chair of Hackney GP Forum

We recently met with Dr Gaby Tobias who is a GP in Hackney and also joint Chair of Hackney GP Forum. The GP Forum is open to all GPs in Hackney and meets once a month to discuss implications of government legislation, issues in primary and acute health care and to reach a consensus on how to take action to lobby for change.

We asked Dr Tobias to share with us her views on the introduction of **Primary Care Commissioning** (following the Government's publication for the White Paper earlier this year), what this might mean in terms of commissioning services for people with disabilities and issues identified by GPs related to services for people with disabilities.

Primary Care Commissioning (PCC)

Primary Care Commissioning Groups will be accountable to the Health Authority and are required to;

- Be representative of all GP Practices in the population they are responsible for
- Have a governing body which includes community nursing and social services as well as local GPs
- Take account of Social Services and Health Authority boundaries
- Contribute to and abide by the local Health Improvement Programme
- Have clear arrangements for public involvement including open meetings
- Have efficient and effective arrangements for management and financial accountability

The PCG's will be in operation by April 1999 and all GPs will be members of a group.

"The experience of Primary Care Commissioning (PCC) is new to East London & the City and the Health Authority is waiting for further government guidance before changing existing structures. The White paper however does place an emphasis on the new primary care commissioning groups to consult widely with other agencies, the voluntary sector and users. A Stakeholder day will be taking place on April 30, to which representatives

of the voluntary and community sector will be invited". "At this stage it is unclear as to how users will be directly involved in PCC but is **important that proper involvement by all the voluntary sector and users takes place effectively in PCC to ensure that the needs of Hackney's diverse communities are properly taken into account**".

GP Issues

"Community Care Teams based in practices take a holistic view of patients needs and work across social and health care services to help patients access appropriate services. Disability is becoming a greater issue as the **recent government changes to benefits place greater responsibility with the GP to interpret disability**. The administrative workload of GPs has increased tremendously over the last ten years and **more practice based Benefits Workers** are needed to advise patients on obtaining benefits".

"With the diverse cultural and ethnic mix in Hackney **GPs need better access to interpreting services facilities** to help diagnose and treat patients more effectively. Currently GPs all too often have to rely on patients bringing in a friend or family member to interpret between the GP and patient. The Health Authority does currently provide a telephone interpreting service called Language Line, although GPs are charged for making use of the service. It is hoped that more resources will be identified through the Health Authority's advocacy review to help with this".

"Grants are available to GPs from the Health Authority for all practices which are renovating or moving into new premises to **make buildings accessible to people with disabilities**. Practices are therefore increasingly becoming more widely accessible to people with disabilities". If your practice is not accessible to you you should contact the Health Authority on: 0171 633 6600 who will be able to inform you of which GP practices are accessible.

For a copy of the White Paper summary contact Rimple

Next meeting of Hackney Community Care Forum

The next meeting will be taking place on:

Wednesday 22nd April, 11 - 1pm
at The Barnabas Centre, 109 Homerton High St E9.

Speakers: Adiaha Antigha (Director of HCVS) and Eve Old (Locum Contracts Manager - Older People LBH)

Topic: the Council's Voluntary Sector Review

The Review will involve a **fundamental look at the Council's funding to the voluntary sector** and how it will fund groups in future. Council officers have stated that funding will possibly be taken away from groups who do not meet their **"best value"** criteria. If you are a health or social group and would like to find out more about this review or address health & social care issues in Hackney then come along to the next meeting. For more information about the Forum contact: **Rimple at HCVS tel: 0171 923 1962**

East London declared a Health Action Zone!

East London and the City Health Authority (ELCHA) as been awarded Health Action Zone (HAZ) status along with ten other areas across the UK.

ELCHA's HAZ focuses on;

- **young people** - investing in "tomorrow's adult population and equipping today's adults ..to give their children the best chance of a healthy future"

and on tackling major causes of illness;

- **mental health**
- **heart disease**

The HAZ aims to achieve these targets after 7 years;

- unemployment in young men under 25 from ethnic minority communities reduced
- death rates from coronary heart disease and stroke in under 65's reduced
- numbers of people aged 18 - 30 admitted as mental health in-patients reduced
- computerised information systems with shared data between GPs, health and social care agencies and the public developed.

The HAZ aims to tackle the root of ill health through **tackling wider issues such as unemployment, housing and education**. It is not clear at this stage how much money the HAZ will bring into East London but it clearly provides a much needed opportunity to tackle deprivation and ill health in East London and new ways of working across traditional organisational boundaries.

We anticipate that local voluntary groups will be recognised as significant partners in the process of regenerating people's health in East London. The Health Authority will not be able to achieve its targets without actively involving the voluntary sector and it' goal of effecting permanent improvements in the health and well being of some of the most diverse, disadvantaged and yet vibrant communities in the UK."

For a copy of the HAZ bid contact: **Rimple at HCVS**

Fundraising help for Groups cut by ELCHA

Two Fundraising Consultants have been appointed by HCVS for a year to help groups secure funding. £2.6 million cuts were made to voluntary groups by the Health Authority last year.

Marika Mason and **Elizabeth Bayliss** will be working with groups to save vital services in Tower Hamlets and Hackney, thanks to funding from **Bridge House Estates Trust Fund**.

Get Your Views Known! Disability Voluntary Sector Representatives in Joint Planning

The **Disability Joint Executive Team (JET)** meets once every two months to formulate proposals and address needs through joint planning for the provision of Disability services in City & Hackney.

Membership of the Disability JET includes representatives from the London Borough of Hackney, East London & City Health Authority, City & Hackney NHS Community Services Trust, Homerton Trust and three representatives from the voluntary sector.

The voluntary sector representatives are **elected at Hackney Community Care Forum's AGM** and for 1997 - 98 are Mary Julian (TLC), Caroline Nelson (CHOICE) and Dai Powell (Hackney Community Transport). They are responsible for taking forward needs, issues or gaps in Disability services which have been identified by voluntary and community groups, into joint planning through the JET. Issues discussed at the last meeting included:

- **Direct Payments Scheme** - no upper limit has been set for the initial intake and three people have expressed interest in joining the scheme. Direct Payments will only be available to those reviewing care packages involving personal care and not to those who only receive support with shopping or cleaning.
- Discussion on **C & H Community NHS Trust's Review of Disability Services** - The Trust are keen to work with the Disability Users Forum to progress some of the action points emerging from the review. Clarification was sought by a voluntary sector representatives that people who were purchasing physiotherapy privately would not have their NHS provision removed. The Trust representative clarified that this would not happen.
- **Lal Heaton (Chair of the JET)** is working to ensure that Health and Local Authority contractors comply with the Disability Discrimination Act - the Disability JET will monitor this.

If there are issues around Disability that you think need addressing please contact any of the JET representatives:

Mary Julian	Tel: 0171 729 6335
Caroline Nelson	Tel: 0171 613 3206
Dai Powell	Tel: 0171 275 0012

or **Rimple** at Hackney CVS on: **0171 923 1962**

Volunteering is a right that should be available to every member of our community. HAVE's "Volunteer Working Rights" which all registered organisations sign up to states that **volunteers should not be discriminated against on the grounds of sex, race, sexuality, age, class, disability, history of illness.** Volunteering is not just about delivering services but also about community involvement, inclusiveness and empowerment.

The Hackney Situation

Requests for volunteering referrals received by the Hackney Agency for Volunteering (HAVE) from people with physical disabilities (4% of total referral requests) closely mirror the proportion of people with physical disabilities in the Borough (5%) as reported by the London Borough of Hackney (1996). HAVE receives requests for volunteer referrals directly from people who self-classify themselves as being disabled and from key workers of clients who have disabilities. The majority of people are looking to volunteer as part of their efforts to re-enter the workforce or to give something back to the community and develop their skills and interests.

More Volunteer Placements Needed!

In Hackney, there is a lack of volunteering placements for people with disabilities. Sometimes organisations, especially smaller organisations, tell us that they do not have the resources to accommodate people with extra support needs - either because of limitations on current staff time, access difficulties and/or space restrictions. There has even been some difficulty in finding placements when key workers are willing to assist their client with the volunteering activity.

Some local organisations who provide volunteering opportunities for people with extra support needs have also commented on the shortage of placements.

- **Hackney and City Mind's Volunteer Placement Scheme**, arranges volunteer placements for people who are experiencing, or who have overcome a period of emotional distress. Call: 0181 985 7965 for details.
- **Macintyre Care's Hackney Volunteer Project**, involves people with learning difficulties in volunteering activities. Call: 0171 613 9172 for information.

Both programmes have mentioned that it is sometimes difficult to find appropriate placements for their volunteers - especially **meaningful placements** that will utilise the volunteers skills and interests. These programmes also involve volunteer befrienders who assist in supporting the volunteers with extra support needs in their placements. For more information about becoming involved in these programmes please **contact them directly or call HAVE for additional opportunities.**

Difficulties Experienced by Disabled Volunteers

Articles in Volunteering (National Centre for Volunteering's newsletter) **highlight some frustrations and difficulties** people with disabilities experience when volunteering. An article in the March 1998 edition focuses on concerns raised by people with mental health issues who volunteer to write newsletter articles. Those on Incapacity Benefit are **worried that they would be accused of doing too many volunteer hours** by the Department of Social Security.

The article points out how bureaucratic the current benefits legislation can be and how difficult it often is to receive clarification in regards to volunteering. The solution was that volunteers would send an official letter to their benefits office before starting to volunteer and send off a weekly pro-forma of volunteer hours worked. These hours would be calculated on a rolling average of five weeks to allow weekly hours to vary - with the average conforming to the allowed 16 hours per week.

This is especially an important issue for people with mental health issues since the unpredictable nature of feeling better or worse makes it difficult to keep to regular schedules. Another article in the Feb 1998 edition of Volunteering "**Volunteers with extra support needs: Adam May** outlines the main issues to consider", points out that Volunteer Co-ordinators **need to take into account the functional ability** (i.e. what they can do) of volunteers with extra support needs rather than assessing them using labels such as "schizophrenic" or "ex-offender". Adam May also states that **volunteering can be about promoting social change** and that Volunteer Co-ordinators can challenge their organisations to ensure that commitments to equal opportunities policies become a reality!

Mapping Needs

HAVE is about to start a **mapping exercise of current volunteering opportunities for people with disabilities** in the Borough so please call us to have your organisation included in the resulting directory. Several Volunteer Bureaux have secured funding for a Volunteer Support Worker to assist volunteers with extra support needs. Please let us know if you would find this additional support for your volunteer programme useful in allowing you to become more inclusive!

Volunteering and Your Benefits

Incapacity Benefit (IB), Severe Disablement Allowance (SDA)

These benefits are paid to people unable to do a full-time job because of sickness or disability. You first must let your Social Security office know before you start volunteering. You may be able to do some voluntary work if it totals less than an average of 16 hours a week. The volunteering work must be for someone other than a family member and you must only accept reasonable "out of pocket" expenses.

Disability Living Allowance (DLA)

Voluntary work does not normally affect payment of DLA. But, if you are able to do this work because your condition has improved you should inform your Social Security office.

Disability Working Allowance (DWA)

To get DWA you must be working at least 16 hours a week and have an illness or disability which limits your earning capacity. Work as a volunteer does not count towards your 16 hours.

Invalid Care Allowance (ICA)

Volunteering does not affect ICA unless it stops you caring for the disabled person for at least 35 hours a week.

Industrial Injuries Disablement Benefit and Reduced Earnings Allowance

These benefits are not affected by voluntary work.

Additional Information

The National Centre for Volunteering offers courses on "Disabled people and volunteering". Call Audrey Benjamin on 0171 388 9888 for details.

Useful leaflets available from DSS offices are: "Incapacity Benefit and The All Work Test", ref IB214 and "Voluntary and part-time workers" FB26.

Involving Volunteers with Extra Support Needs: A self-study pack for volunteer organisers, Hinckley Area Volunteer Bureau.

These materials are also available in **HAVE's Resource Centre** (copies of the leaflets are also available through HAVE) along with a leaflet called "Jobseeker's Allowance: Voluntary work when you're unemployed and it needn't affect your benefits!". For more information call Hackney Agency for Volunteering on: 0171 275 6747

Volunteering Can Help You!

Volunteering should be reciprocal and help to build communities. Volunteering is a two way street - **volunteers should get as much out of volunteering as they contribute to the organisation.**

It is all about everyone participating in their community to make it a better place to live. Hackney Agency for Volunteering serves to strengthen the community by mobilising people and resources to deliver creative solutions to serious social problems. This is accomplished through all people in the community working together - especially people with extra support needs who are often not recognised for their important contributions to society.

Please ensure that everyone who would like to be involved with your organisation has that right!

For further information and advice on volunteering please contact: **Hackney Agency for Volunteering on: 0181 275 6747 or 0181 275 6746**

Volunteer Time (in kind) for match funding

Volunteer time has been accepted as having a financial value by the European Commission. This is an important precedent - if it has been accepted by Europe, we can argue that it should be accepted by local authorities.

The financial value of different sorts of volunteer time is precisely specified hourly and annually i.e. a project manager's time is calculated as £24,000 full-time. Specialist input, such as that of volunteer signers is accepted and we think that Management Committee member's time can also be costed in.

There is a requirement for the time spent to be carefully recorded. Volunteers will sign time sheets to confirm their attendance time and the agency will prepare notional invoices for the cost of volunteer time in the project.

Call **Hackney CVS** for more details
Tel: 0171 923 1962

Support for Groups

If you would like assistance in reviewing your volunteer programme to make it more inclusive - HAVE can assist you with developing opportunities that could involve all members of our community.

Please call us on 0171 275 6747.